

**2005 White House
Conference on Aging**

*Post Event Summary Report
Independent Aging Event*

Name of Event: A Call for a Revitalized National Mortality Followback Survey

Date of Event: July 19, 2005

Location of Event: Russell Senate Office Building, Washington, D.C.

No. of Persons Attending: 45

Sponsoring Organization: Americans for Better Care of the Dying

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Priority Issue #1

End-of-life care is among the most neglected of the public policy issues facing us today. It is one that we, as a society, are good at avoiding. We lack the most basic details of how people spend their final months and days – whether they are cared for according to their wishes or not, whether they are in pain or not – and the means to monitor whether, as a country, changes in the health care system result in improvements. Accordingly, we have an urgent need to collect information systematically on how well or how badly Americans fare as they approach the end of life. Based on anecdotal evidence and sporadic studies, we have learned that for a large minority—if not the majority—the end of life could be far better lived, and probably at less cost to the Government and at less financial and emotional cost to families.

Currently, health care for people in their last year of life accounts for more than one-quarter of Medicare spending – an average of \$25,000 per decedent. In addition, there are out-of-pocket costs for many families. Even greater costs are the emotional trauma to the family, friends, and, often, to the patient during this final period of life. Yet, our knowledge about this period of life is pitifully, and inexcusably, limited. Indeed, the dearth of information makes it all but impossible to understand why things go wrong for those near death, or to structure public policy to improve the situation for coming generations.

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With reliable information about care and the quality of life, we would be able not only to judge how well we are coping today, but also to plan for health service needs in the coming years. The main uses of this information are for (1) public accountability, that is, allowing policymakers, patients, families, and the public to hold organizations and individuals accountable for the quality of care they provide to dying patients, (2) internal quality improvement efforts by clinicians and others directly responsible for end-of-life care to evaluate and improve what they are doing on a continuing basis; and (3) further research on the effects of different clinical, organizational, and financing options for end-of-life care and on the effectiveness of alternative strategies for improving care and outcomes for patients and their families.

Barriers

No technical barriers block the way to filling a large portion of this information void. The proposed solution to this need for data is simply the revitalization of a previously established federal survey, the National Mortality Followback Survey (NMFS). The methodology for data collection in the proposed solution is feasible, tried and true, based on U.S. experience in conducting similar, though sporadic surveys, over the past 40 years. The major barrier is financial: the proposed revitalization of the NMFS will cost \$7.5 million annually. Most of this funding is devoted to planning and operating the national survey, while some funding is for linking NMFS records to other surveys and administrative data, including Medicare and Medicaid claims, tumor registries, and national long-term care surveys. Some of the funds also support the National Vital Statistics System through which death certificate information from each of the States is compiled.

Proposed Solution

A National Mortality Followback Survey (NMFS) that gathers data each year is the most cost effective and efficient way to inform the Nation about the quality of life and quality of care that Americans experience at the end of life. This is not just our opinion: after thoroughly investigating the alternatives, authoritative reports from the Institute of Medicine of the National Academies (2001, 2003) and the highly-respected Robert Wood Johnson Foundation (2004) independently came to the same conclusion about the need for a continuous NMFS. The recommendation was endorsed by a December 2004 National Institutes of Health State-of-the Science Conference on *Improving End-of-Life Care*. The reason for the consensus that the NMFS is the best solution to collecting information about the end-of-life is that, unlike any other data method, it focuses directly on persons who have died. In contrast, most other data collection surveys include relatively few persons who are nearing death; indeed, only about 1 percent of the population dies every year, so the number of persons approaching end of life in general surveys is usually far too small to yield detailed and reliable information. For that reason, the “followback” methodology has been selected as the best approach to filling our Nation’s information gap about how we die, that is, the circumstances and impact of the end-of-life experiences of Americans.

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While the NMFS is a national survey, over time the cumulative numbers in the sample will grow sufficiently to yield regional estimates and, for some of the larger States, estimates for those States. However, we believe end-of-life information is also critical for States; so this project will also promote Federal-State partnerships to help States develop their own surveys using the NMFS as a model. Such collaboration has been demonstrably successful in collecting information on behavioral risk factors at the State level; as of 1994, all the States had begun participating in the national behavioral risk factor survey conducted by the U.S. Centers for Disease Control.

How Does a Mortality Followback Survey Work?

A sample of death certificates of people who died in the previous year is selected and information is collected by interviewing the next of kin or someone close to the decedent (a “proxy”). Information from the death certificate and from other records that can be linked *electronically* are added to enrich the survey. The most important electronic records are claims made to Medicare during the period before death, but additional data sources that can be linked to the NMFS include Medicaid, tumor registry information, hospital records, and other surveys related to health care.

Getting a complete “sampling frame” of everyone who died is possible because each State reports all deaths occurring in that State to the National Center for Health Statistics (NCHS, part of the Centers for Disease Control). Next of kin is listed on the death certificate, so the search for someone knowledgeable about the decedent’s last months and days begins with that person. The “followback” methodology is highly efficient compared with other survey types because each person in the sample is guaranteed to contribute information about life in the period before death. Any representative survey of people still alive—even if we think they may die soon—captures only a small portion of the dying experience. Of course, other studies and surveys will always be needed to fill in various details, but there is no better way than the NMFS to paint the big picture. Moreover, we can take the large number of cases in the NMFS and link them to the limited number of cases in general surveys to not only obtain additional information, but also to validate the information in the NMFS.

What Experience Do We Have with Followback Surveys?

The NMFS is not a new idea. NCHS conducted six such surveys between 1961 and 1993, but each had substantially different aims. They delved more broadly into lifestyle and earlier risk factors for disease than into the period leading up to death. Even so, they were rich mines of information that gave insight into living and dying in America and provided useful information to policymakers. Researchers still use data from the 1993 survey, but the experience of people dying half a generation ago is of dwindling relevance today, and cannot be the basis for monitoring changes over time.

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The proposed “revitalized” NMFS will be carried out by NCHS, with a focus on quality of life and quality of care during the final months of life, but will retain some of the key topics of previous followback surveys. Importantly, the revitalized survey will maintain a core of unchanging questions, so that trends can be identified over time. It would also be linkable with administrative data, such as Medicare claims, to enhance the range of health and health care topics it could address. Carrying out the study every year means minimal start-up costs once it is up and running, and the ability to gather and pool data year-to-year means that annual sample sizes can be smaller than in the ad hoc followback surveys of the past. As with all other NCHS surveys, the data would be made publicly available in familiar formats for researchers.

What Will We Learn from the Revitalized NMFS?

We know that the NMFS can be a rich resource for policymakers and researchers. To pick out just a few items, the NMFS can provide information for planning and to guide policy on at least the following topics:

- Rates and duration of disability, long-term care and chronic illness
- Dying experiences of special populations, such as children and certain minority groups
- Medicare utilization and costs by medical condition and demographic group
- Factors associated with the spend-down to Medicaid eligibility
- Medicare spending patterns for those dually eligible for Medicare and Medicaid
- Medicare spending patterns before and after entering the Medicare hospice program.
- Projections of chronic illness, disability and long-term care for current and future cohorts
- Consequences of changes in public policy such as the recent changes in financing home health care
- Differentials in end-of-life care by socioeconomic status, race or ethnicity, and geography

How Much Will the NMFS Cost?

As we indicated, the key barrier to a continuous NMFS is not technical; it is financial. An assured, continuous, source of funding is a necessity. The revitalized NMFS conducted by NCHS will cost about \$7.5 million per year (2005 dollars), including the cost of electronic linkages with Medicare and other data bases.

Reports Containing Additional Detail and Support for a National Mortality Followback Survey Focusing on End-of-Life Care

Institute of Medicine. Describing Death in America: What We Need to Know. June Lunney JR et al. Washington DC: National Academy Press, 2003.

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Institute of Medicine. Approaching Death: Improving Care at the End of Life. Field MJ, Cassel CK, editors. Washington DC: National Academy Press, 1997.

Institute of Medicine. Improving Palliative Care for Cancer. Foley KM, Gelband H, editors. Washington DC: National Academy Press, 2001.

Last Acts Partnership (supported by the Robert Wood Johnson Foundation), A Call for a Revitalized National Mortality Followback Survey. Washington DC, 2004.